

# Cancer and ethnic minorities - the Department of Health's perspective

V Bahl

Adviser in Ethnic Minority Health, Department of Health

**Abstract** With more than 160,000 deaths annually cancer is the second commonest cause of death in the UK. The little evidence available shows that black and minority ethnic people are experiencing an increase in cancer-related mortality. The Government's Health of the Nation report produced in 1993 by the Department of Health identifies key areas, including cancer, where improvements in mortality and morbidity could be achieved, and an essential element relates to the needs of black and minority ethnic people. It is, for example, now well recognised that in terms of screening, treatment and palliation, cancer services are not always accessible and sensitive to the needs of this section of the population.

Beginning with a demographic backdrop this paper reviews the data on the occurrence of cancer and on access to services by this section of the population. Relevant initiatives funded by the Department of Health are highlighted and a summary of the information sources to enable health care purchasers and service providers to assess the needs of their local population has also been given.

## Demography: The minority ethnic population in England and Wales

Ethnic minorities comprise 6% of the total population in England and Wales: just under a half are from the Indian subcontinent (India, Pakistan or Bangladesh); one third are Afro-Caribbean or African, and 5% are Chinese<sup>1</sup> (Figure 1).

The age structure of minority ethnic communities differs from the majority white population in being much younger; this is especially evident among Bangladeshis and Pakistanis. (Figures 2a-d and 3) The ratio of males to females varies both by ethnic group and age. Among Pakistanis, Bangladeshis and Black African communities, men outnumber women by nearly 10%; in contrast women outnumber men by a similar figure in Afro-Caribbean, African and Chinese communities. These differing age structures and male/female ratios among Pakistani and Bangladeshi communities reflect the in-migration of males in recent years.<sup>2</sup>

The majority of minority ethnic communities generally live in urban areas and have tended to reside in particular towns and cities; thus Afro-Caribbeans, Africans and Bangladeshis live predominantly in the Greater London area, especially inner London. One third of the Indian community lives in the outer London suburbs with the remainder being principally found in the West Midlands and Leicestershire. Most people of Pakistani origin live in the West Midlands and Yorkshire with a smaller proportion being found in London. By contrast, Chinese communities are widely dispersed throughout England and Wales. Table I lists the 20 Health Commissioning Authorities with the highest proportions of black and minority ethnic

**Table I** The ethnic minority population as a percentage of the district/borough total population

District/Borough	Percent	District/Borough	Percent
Brent	44.8	Waltham Forest	25.6
Newham	42.3	Hounslow	24.4
Tower Hamlets	35.6	Southwark	24.4
Hackney	33.6	Lewisham	22.0
Ealing	32.3	Birmingham	21.5
Lambeth	30.3	Redbridge	21.4
Haringey	29.0	City of Westminster	21.4
Leicester	28.5	Wandsworth	20.0
Slough	27.7	Luton	19.8
Harrow	26.2	Islington	18.9

Source: 1991 Census County Monitors CM1-CM54.

residents in England.<sup>2</sup>

Demographic data for minority ethnic communities have (potentially) important applications for health service provision, future trends in disease incidence and identification of risk factors for particular diseases.

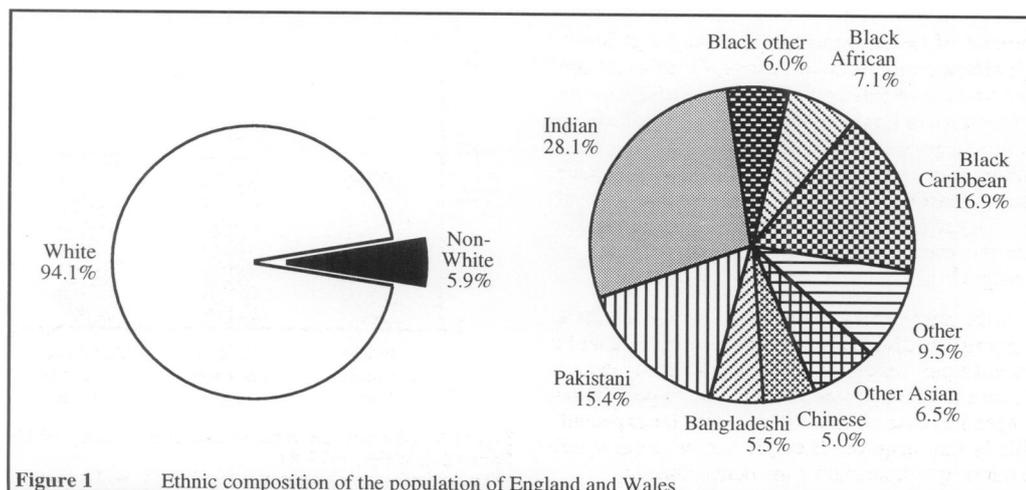


Figure 1 Ethnic composition of the population of England and Wales

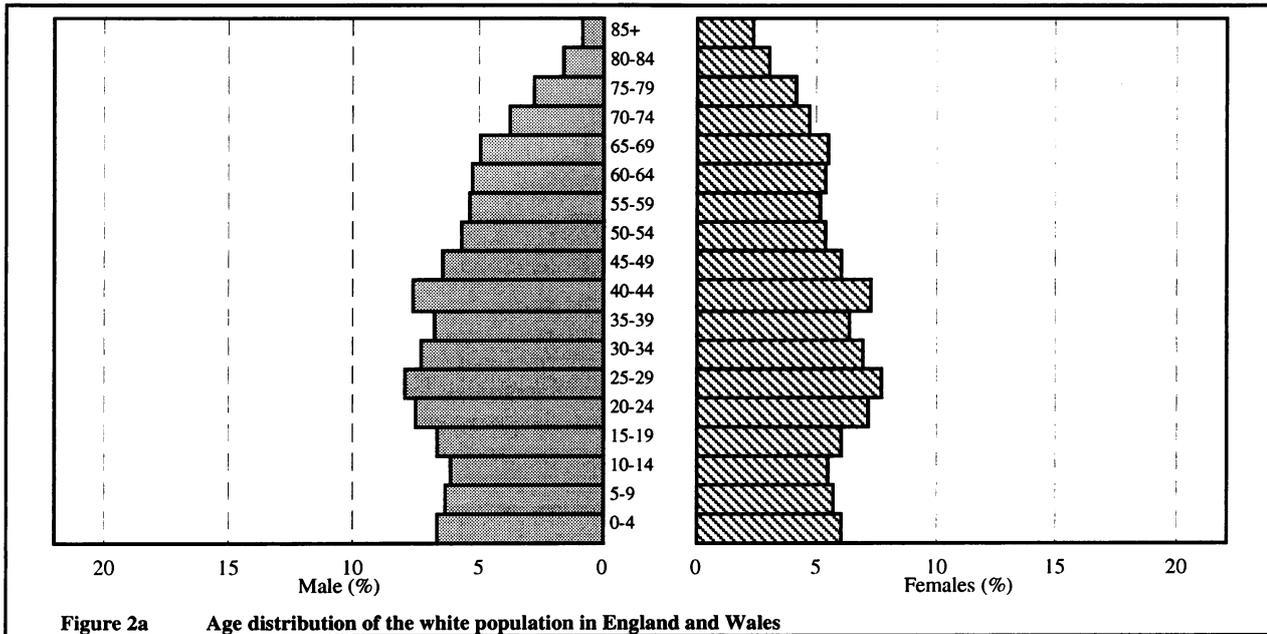


Figure 2a Age distribution of the white population in England and Wales

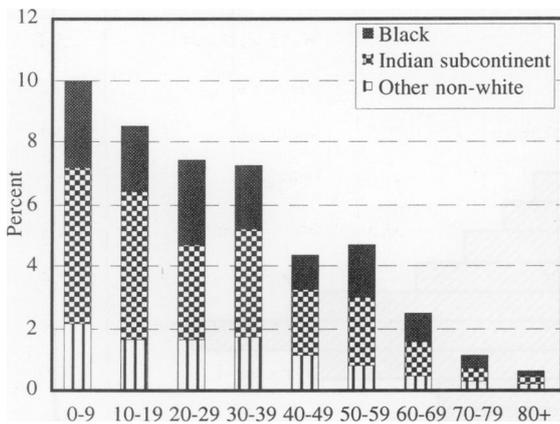


Figure 3 Shows the percentage of the population at each age group that is non-white in England and Wales.

**The epidemiology of cancer in black and minority ethnic communities**

Current data on cancer suggest that mortality from cancer for minority ethnic communities is generally lower than for the majority white population; these figures are, however, of limited applicability since they relate to migrants (mainly from the African and Caribbean Commonwealth and the Indian subcontinent) and not individuals born in England and Wales.

The recent Department of Health report on ethnicity and health suggests a lower incidence of cancer in Asians, Caribbeans and Africans<sup>3</sup>. The report also identifies that, in comparison to the white population, mortality in England and Wales from breast and cervical cancer is low in people born in the Indian subcontinent and African Commonwealth and, although Caribbeans also have low death rates from breast cancer, their mortality from cervical cancer is raised. (Figures 4 and 5). A study carried out in Bradford confirms the low mortality rates amongst women of South East Asian origin<sup>4</sup>.

It is likely that over the next decade the number of cancer deaths will increase among individuals from minority ethnic communities; this is in part an effect of ageing - cancer deaths occur mainly in those aged 55 years and above, and as population numbers at these ages increase so more deaths will be expected. In addition it is likely that acquired lifestyle and environmental factors will cause minority ethnic cancer incidence rates to

approximate to those of the majority white community<sup>3</sup>.

Although current mortality from lung cancer is low in black and ethnic minorities, (Figure 6) there is evidence from the Health Education Authority's (HEA) lifestyle survey that smoking is a considerable risk factor for ethnic minority men. Afro-Caribbeans and Pakistani men have smoking levels similar to the UK average and Bangladeshi men have significantly higher than average rates for smoking<sup>5</sup>.

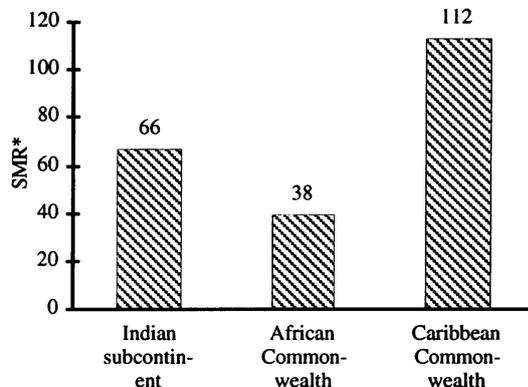


Figure 4 Mortality from cervical cancer by country of birth (ages 20-69) England & Wales 1979-83  
\*Standard Mortality Ratios with England & Wales = 100.

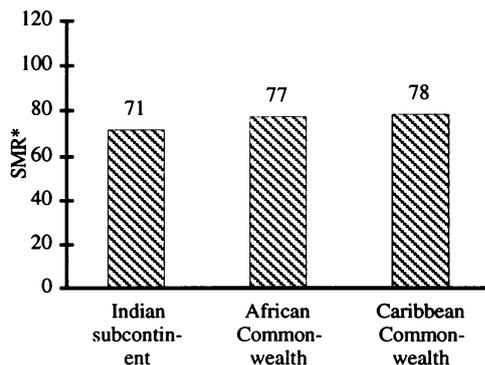


Figure 5 Mortality from breast cancer by country of birth (ages 20-69) England & Wales, 1979-83.  
\*Standard Mortality Ratios with England & Wales = 100.

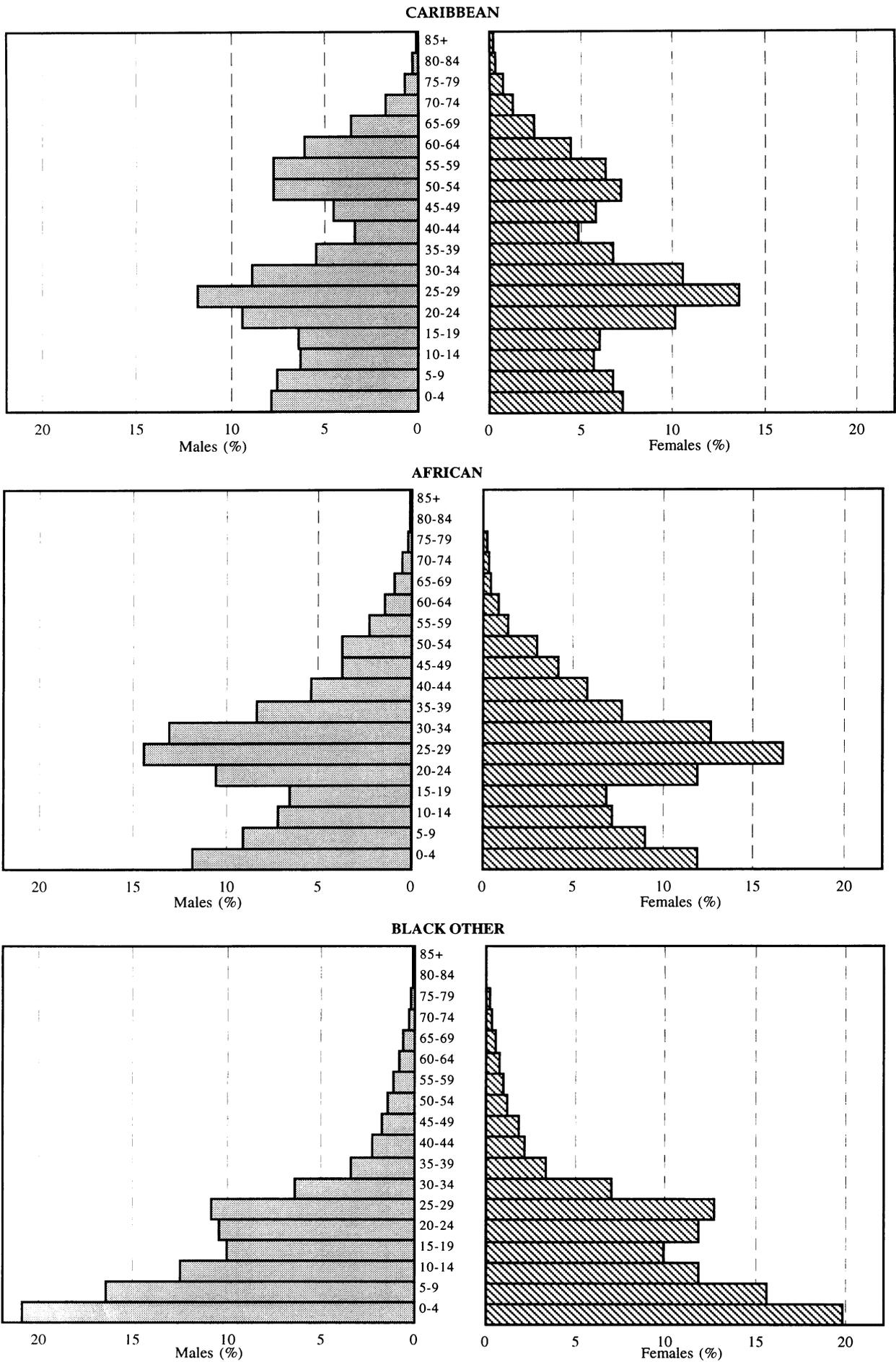


Figure 2b Age distribution of the black population in England and Wales

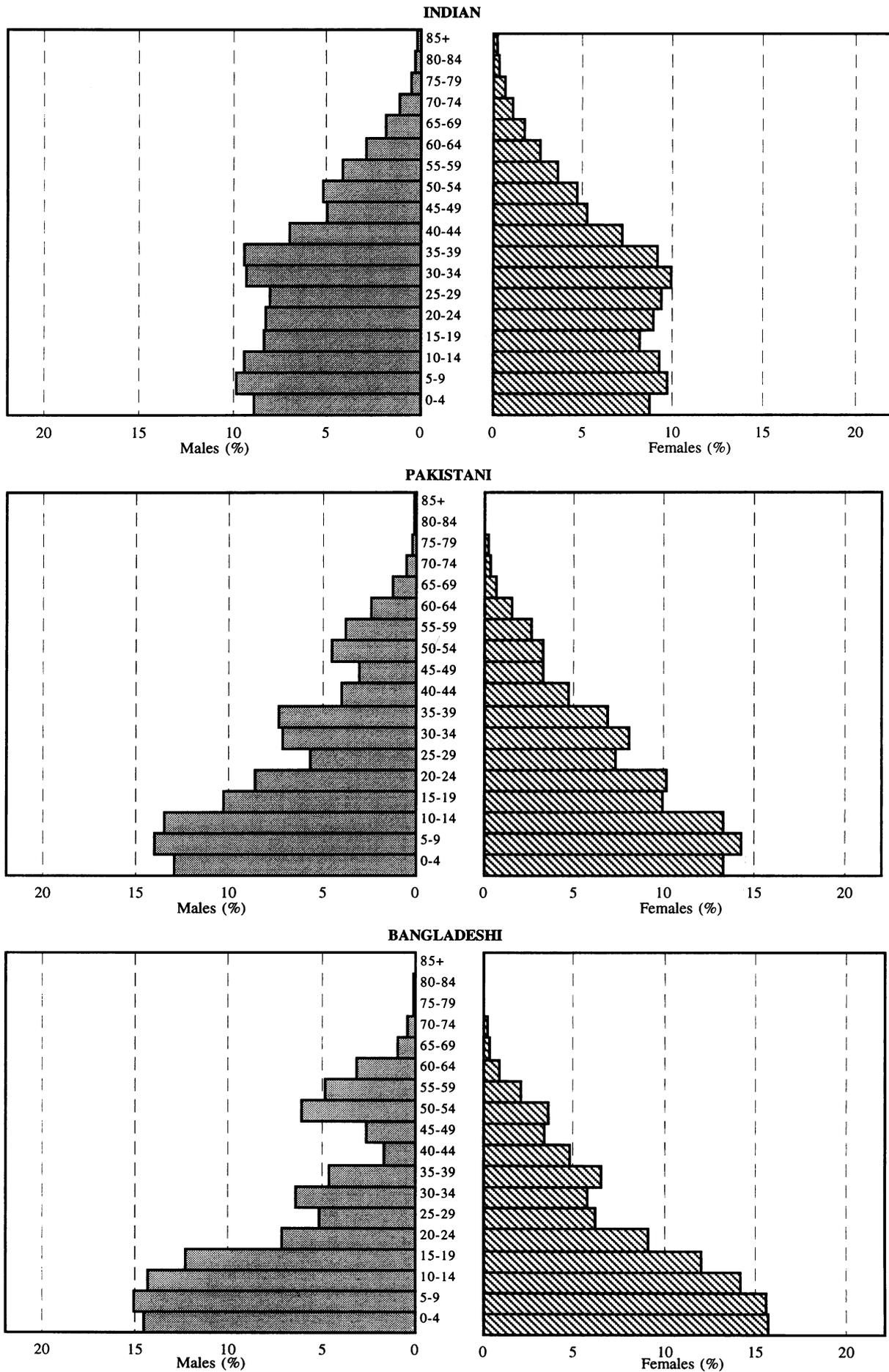


Figure 2c Age distribution of the Asian populations in England and Wales

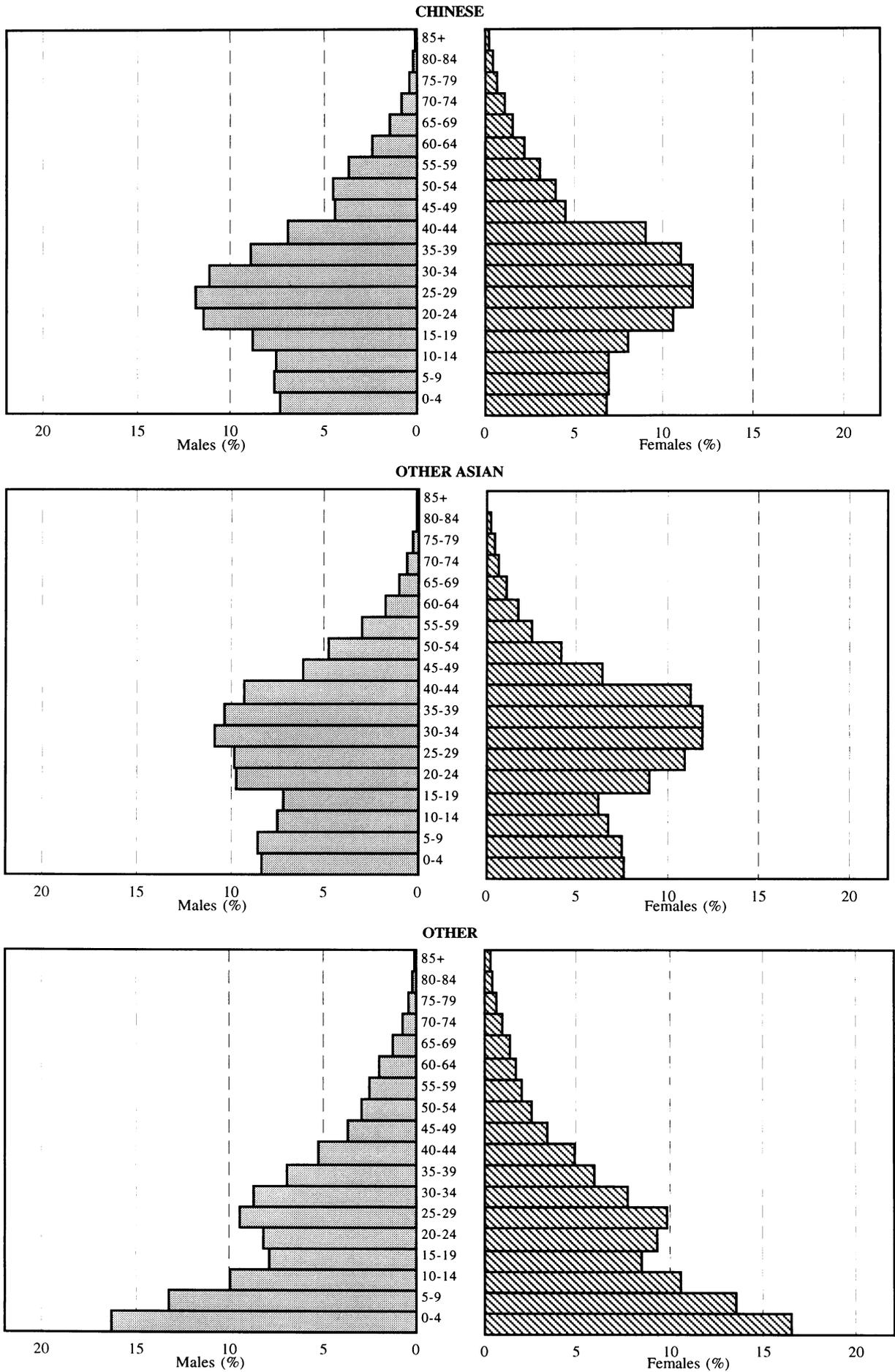
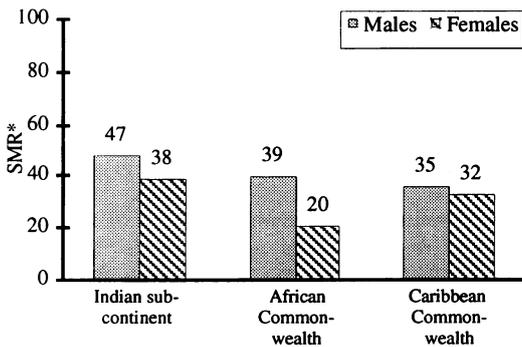


Figure 2d Age distribution of the Other populations in England and Wales



**Figure 6** Mortality from lung cancer by country of birth (ages 20-69) England & Wales, 1979-83.

\*Standard Mortality Ratios with England & Wales = 100.

Oral cancers have a high prevalence in the Indian sub-continent. However, in the absence of ethnic group monitoring, the extent to which this is the case in the Asian community in the United Kingdom is not known. The evidence from small scale studies indicates that there is a widespread use of chewing tobacco, which is known to be carcinogenic, in the Bangladeshi community.<sup>6</sup>

Although the launch of the Government's Health of the Nation initiative<sup>7</sup> has stimulated considerable interest from both purchasers and providers, relatively little attention has been given to the occurrence of cancer in minority ethnic groups. The launch of national screening programmes on breast and cervical screening has however raised awareness among researchers, policy makers and increasingly the NHS should address the issue of screening in relation to ethnic minorities.

#### Ethnic sensitivity in cancer services

As the following discussion illustrates, to be effective, cancer prevention and treatment programmes will need to be sensitive to the beliefs and attitudes, values and lifestyle of the social groups at which they are aimed.

Attitudes towards cancer will influence uptake of preventive measures and health services and is therefore a good starting point for this discussion. Although this is gradually being disputed, the idea that cancer creates a set of emotional responses peculiar to the disease still holds sway. It has, as a disease, been feared as a silent invader - a disease which often causes agonised suffering and is concealed. Theories of causation from the white majority community have ranged from moral wrongdoing to leading an unclean life. For example, after 7 years of public education in Lancaster,<sup>8</sup> Knopf found that such views were still held by many in the white population. A study by Box<sup>9</sup> reports one third of people interviewed still believing that cancer was either inherited, due to punishment for not taking care of family members, loose living or contagion. It is no surprise therefore that even today there is still much resistance to talking openly about the condition in Britain. This element of guilt, stigma and taboo also exists among some black and ethnic minority groups many of which do not have access to Western scientific medical knowledge: as a modern medical concept the term cancer does not exist in many of the community languages spoken in multiracial Britain.

The above negative and seemingly irrational behaviour towards cancer will be reinforced if the treatment creates conflict within those affected in relation to religious requirements and beliefs. An example of this which readily springs to mind is that of a Moslem patient with faecal incontinence or a colostomy as a result of bowel cancer. Such a situation could present additional stress and anxiety for believers for whom the religion is an all-embracing way of life. Not only would faeces on any part of the body be physically, but also spiritually, polluting. Thus at a time when the

patient would wish to draw on their spiritual strength they are rendered most vulnerable.<sup>10</sup> Similarly the hair loss associated with chemotherapy could be very distressing for Sikhs among whom long uncut hair is a religious requirement. Such cultural and religious outlooks will have implications for the rejection of these treatment options. It is important therefore to work with the individual patient to develop an appropriate care package which reflects their cultural and religious needs.

Death and bereavement are distressing facts of life for everyone. Reactions to grief will be affected by individual as well as cultural factors. Not every cultural group will feel the social pressure to contain their grief which may be the norm in some white communities. Many black and minority ethnic people may also wish to rely on the therapeutic value of the expression of strong emotions and the supportive grieving of others concerned, to help them come to terms with loss.<sup>11</sup> If these issues are not appreciated by service providers however, then being denied the very coping mechanisms traditionally adopted by these communities could result in added distress for those dying of, or bereaved through cancer. Many minority ethnic people who are bereaved may not feel able to openly express their anxieties and emotions for fear of not being understood by health workers who may appear to hold a different set of beliefs and values.

In summarising a discussion on cultural attitudes it would, on the whole, be reasonable to suggest that, as a major cause of death and suffering, knowledge and awareness of cancer is rapidly spreading amongst all population groups in Britain. It is also important to recognise that within any particular ethnic group there are variations to norms and attitudes which are dependent on level of education, socio-economic status, access to medical and scientific knowledge, force of belief system and general outlook on life. No two individuals are the same.<sup>12</sup>

Over the last five years, the Department of Health has funded a number of research projects aimed at developing greater understanding and sensitivity in this area. The following three projects are amongst the most recent. In 1991 Cancerlink, a voluntary organisation which provides information and support to people with cancer and their carers, was commissioned to carry out a study to explore attitudes and expectations and to identify the requirements of minority ethnic groups and migrant workers. The report of the study which was jointly funded with the European Community<sup>13</sup> highlighted that:

Attitudes and beliefs did not differ widely from the majority populations. What was however clearly evident was a lack of knowledge especially among the non-English speaking and older people and there was an eagerness by all communities for more information about cancer and other health-related subjects.

The commonly held belief that minority ethnic families prefer to rely on their own resources and do not need help from outside agencies can result in a lack of support for carers from those communities. The Chinese community was particularly disadvantaged in this way because of their diverse geographical location and lack of support.

The minority ethnic communities were not aware that hospice services existed. Whilst they were however prepared to use such services, they needed assurance that predominantly Christian origins would not preclude hospices from taking account of other religious and cultural needs.

The role of linkworkers and advocates in improving the quality of services both in prevention and treatment was also highlighted.

Birmingham University Department of Dental Health was funded to investigate the use of betel-quid chewing in the Bangladeshi community in the UK. Specific objectives were to explore the prevalence of the activity and the social acceptance and perception of the perceived health risks. The two main outcomes were: firstly, an expert symposium to disseminate the research

findings, to determine the scientific basis of health education messages and to outline research priorities for the future; and, secondly, the development of strategies to improve knowledge, promote positive attitudes and reduce the proportion of the community engaging in the inclusion of tobacco into the betel quid.

King's College London was also recently funded to carry out research into breast cancer in African and Afro-Caribbean women. The study is based on the hypotheses that Afro-Caribbean and African women present with breast cancer at a later stage than women from other communities and that acceptance and compliance with treatment and investigation is reduced in women from these ethnic groups.<sup>14</sup> If these hypotheses are supported, the study will go on to explore variations in attitudes and beliefs which may underlie these ethnic differences in use of services.

### Setting standards in cancer treatment

A recent report to the Department of Health by the Expert Advisory Group on Cancer Services<sup>15</sup> starts from the premise that to ensure the maximum possible cure rates and best quality of life, all patients should have access to a uniformly high quality of care in the community or hospital. The report emphasises the importance of a patient centred approach and puts forward the following minimum standards which should form the basis for the development of cancer services:

- Public and professional education to facilitate early recognition of symptoms of cancer.
- Taking account of patients', families' and carers' views and preferences as well as those of professionals.
- Clear information and assistance with regard to treatment options at all stages from diagnosis onwards in a form they understand.
- Care should be provided as close to the patients' home as is compatible with high quality, safe and effective treatment.
- The psychosocial aspects of cancer care should be considered at all stages.
- Cancer registration and careful monitoring of treatment and outcomes.

The above standards present a suitable model by which to improve services to the whole population including black and minority ethnic people.

The Expert Advisory Group also identified the primary care team as a central and continuing element in primary prevention, pre-symptomatic screening, initial diagnosis, through to care and follow up or, in some cases, death and bereavement, for both the patients and carers. As the following discussions on screening and palliative care services will identify, a number of studies have revealed poor access to primary care services by some minority ethnic groups.

### Screening services

In relation to breast and cervical screening, a number of concerns have been raised regarding uptake of these services amongst minority ethnic women. A survey of Asian women undertaken in Ealing to ascertain reasons for low uptake of cervical screening found that they were frequently unaware of the existence and importance of such services. The study further noted that there were fundamental problems of access and appropriateness of the services.<sup>16</sup> Similar results were reported in a study of Asian women in Leicester, where only half of the respondents to a survey knew what a cervical smear was, and 59% said they had never had one; this low uptake applied equally to Hindus, Muslims and Sikhs.<sup>17,18</sup> Investigations have also suggested that uptake of breast screening is substantially less among Asians.<sup>19,20,21</sup>

A number of recent Department of Health funded studies have also highlighted differences in uptake of services amongst black and minority ethnic women. One such survey carried out in Bradford<sup>22</sup> identified that out of a sample of 1000 minority ethnic women who attended health promotion sessions just under half had not heard of cervical smears, 20% had not heard about breast cancer and two-thirds had not heard of mammography. One in five women had never attended for smear tests and 4 in 5 had not attended when invited for a mammogram. Communication barriers resulted in 40% being non-attenders. The Health Education Authority's Lifestyle survey<sup>5</sup> has also demonstrated that whilst uptake amongst Afro-Caribbean women was very similar to the UK average, the figure from the South Asian communities are significantly lower. Lack of information in the relevant languages and an absence of dialogue and discussions resulted in women being less likely to attend for screening even when translated information in community languages was available.

The Bradford study, was carried out as part of the DoH funded Bradford Breast and Cervical Screening Project which appointed outreach workers to discuss with and deliver screening programmes to the local minority ethnic communities. A major issue identified by this project was that screening as a preventive measure may not always be readily understood or appreciated and that this concept needed to be explicitly explained to women from this section of the population. The work of the project also demonstrated that an improvement in the uptake of breast and cervical screening can be achieved. As a consequence, the Community Trust now employs the outreach workers within their mainstream service.

It is also recognised that for religious and cultural reasons, based on modesty, many minority ethnic women will prefer to discuss women's health issues with a service provider of the same sex.<sup>23</sup> Thus, absence of female doctors and nurses in primary care teams would present difficulties for, or act as a deterrent to, service uptake especially when gynaecological examinations are required.

To build on the work carried out in Bradford, the Department recently funded Cancerlink to develop a project known as 'ScanLink'; the aim of which is to raise awareness about cancer prevention, diagnosis and treatment amongst black and minority ethnic women and to encourage services to be more sensitive to cultural needs. Scanlink works with health authorities and the local communities within the regions to explore ways in which services can be made more accessible. Training programmes to enable local women to facilitate health education sessions within their own communities and the production and distribution of appropriate translated information are a key part of the activities of the project.

### Palliative care

Following a year long study, a recent report on palliative care<sup>24</sup> revealed that these services are generally not known to minority ethnic groups. The report also highlighted the need for hospices and palliative care services to be culturally appropriate and to take into account language, religion, and dietary preferences and the need for appropriate and accessible information. In exploring the reasons for the apparent under-use of palliative care services by this section of the population, the report put forward a number of explanations as follows:

- The lack of accurate data on ethnicity of people using these services
- The fact that many black and minority ethnic people choose to retire in their country of origin at the age when they become susceptible to cancer
- Hospice and palliative care services are primarily aimed at people with cancer and there are relatively fewer black and minority ethnic people with this disorder.

- There is little or no written information available to minority ethnic patients and their carers about these services, and they are also not being advised about them.

The report acknowledges that the need for these services within the minority ethnic population will grow during the next decade as the proportion of people over the age of 55 increases, and sets out a strategy to promote ethnic sensitivity and to assist purchasers and providers in adopting policies to improve access to and uptake of services.

The Government's Patients' Charter which was produced in 1991<sup>25</sup> outlines basic acceptable rights and standards that people can expect from Health services. One standard which has direct implications for the multiracial clientele is that proper consideration is shown in ensuring patients' privacy, dignity, religious and cultural beliefs. The Charter has provided the impetus for purchasers and providers to improve such services to this section of the population

### Community awareness

People will only make use of a service if they see it as beneficial to them and if they have access to it. To improve uptake of services on screening and early diagnosis of cancer it is important therefore that communities are furnished with facts about cancer and services available. There are now improved networks within the minority ethnic communities to disseminate information on health issues. A prerequisite however is the production of appropriate materials. Videos as a health education medium are now well recognised as one of the most appropriate resources for use with this section of the population. To this end, the Department has recently funded a number of videos aimed at improving information on cancer and screening. Three examples are as follows:

- The London Chinese Health Resource Centre has produced a video to inform and reassure Cantonese speaking women about breast awareness and the gynaecological examination.
- A video on breast screening for Asian women has also been produced by South Birmingham Health Authority. The latter explains the purpose and procedure of breast screening in Bengali, Gujarati, Hindi/Urdu, Punjabi and English.
- As a direct challenge to the assumption that the Afro-Caribbean population do not experience cultural and linguistic barriers to services - Sandwell Health Authority was funded to produce a video on cervical cytology aimed at women from this section of the population. This video will be culturally and linguistically appropriate and will be backed up by supporting literature. Another video on breast screening, targeting Afro-Caribbean women has also been funded jointly with the NHS Breast Screening Programme.

In addition a number of radio and television programmes addressing the subject of cancer and screening services have also been funded by the Department as a means of encouraging the development of discussions and debate in the community.

As part of the Department's wider concern about cancer, Marie Curie Cancer Care and the Standing Conference of Ethnic Minority Senior Citizens have been funded to organise a course entitled "Talking About Cancer". The aim of the course is to provide training in cancer awareness, including prevention, early detection, screening, diagnosis and palliation. One outcome of this is that a training pack has been prepared for use by community volunteers working with ethnic minority senior citizens.

### Information to assist in the development of appropriate services

Lack of information on minority ethnic groups has made it very difficult to understand local populations at the purchaser and

provider levels. This situation should however be improved as a result of the recent DoH initiative in developing an information strategy on minority ethnic health.<sup>26</sup> The main developments within this strategy are the 1991 Census, the inclusion of ethnic group data as part of the contract Minimum data set and the King's Fund Database.

The 1991 Census is providing better information on the minority ethnic population. The census shows the location of minority ethnic populations across the country. This information is analysed at regional, borough and ward levels to assist the planning and evaluation of the appropriateness and effectiveness of service provision.

From 1 April 1995 it became mandatory to include ethnic group data as part of the admitted patient care contract minimum data set. The collection of ethnic group data will enable purchasers and providers to examine the uptake of services, monitor standards, identify gaps in service provision and ascertain particular needs in the secondary care area. This information will be particularly important for the purchasing organisations to conduct needs assessment. A recent report commissioned by the Department of Health<sup>27</sup> highlights that needs assessment can be supported through these new data by:

- linking patterns of morbidity with specific minority ethnic groups, for example, linking tongue or mouth cancers with groups of people who chew 'bhang'
- comparing national epidemiological profiles of ethnic minorities with the local profile
- comparing local profiles with epidemiological data from countries of origin of specific groups.
- identifying unusual profiles, for example the incidence of cervical cancer in some groups of Asian women
- looking for patterns of inherited conditions.

In order to strengthen the information base on ethnicity and health to support health service researchers, service providers and planners, the Department has funded a database at the King's Fund Centre. The primary function of the centre known as 'SHARE' is collating information on minority ethnic health. This database, which is used extensively by the health services and the voluntary sector, includes epidemiological data and information about initiatives established to address minority ethnic health issues within the statutory and voluntary sectors.

### Conclusion

Cancer is a major killer of people from black and minority ethnic groups. The cultural, linguistic and religious backgrounds of many black and minority ethnic people may result in them having different expectations and experiences of services from their white counterparts. An appreciation of these factors is therefore essential in the planning and development of cancer services for different minority ethnic groups.

Purchasers and providers have a responsibility to develop such an understanding in order to enable services to be more closely matched to individual needs. In addition, because cancer primarily affects elderly people, language and communication barriers will also need to be addressed particularly in terms of explaining the concepts of screening and services available.

Research such as the study from Bradford reported later in these Proceedings,<sup>28</sup> has shown that uptake of services can improve if they are delivered in a culturally sensitive way. As demonstrated in this paper, the Department of Health has made a start in a number of ways to develop this area of work. These include the provision of better information about minority ethnic patients particularly through ethnic monitoring, funding projects to develop good practice and disseminate information, and developing advice to purchasers and providers on delivering appropriate services to meet the needs of minority ethnic groups. It is recognised however that further research is required coupled with monitoring of cancer rates in this population.

### Acknowledgements

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